



MY DATA
OUR HEALTH



My Data Our Health

Launching a public conversation on data privacy and personal responsibility for collective well being

According to some estimates 30% of all data produced is generated by the healthcare industry¹. Yet most people are still unaware of how this data is collected, who is collecting it, where it is being stored, what it is being used for, and why. As individuals our rights to own and control our health data and our responsibilities to make this available to health planners and researchers, are not clearly defined or implemented across most countries.

¹ https://www.rbccm.com/en/gib/healthcare/episode/the_healthcare_data_explosion



NivalishePad initiative is launching the My Data Our Health campaign on health data and our ownership over it with [Transform Health](#). We are inviting our community to join us and to take part in the public conversation on health data on the following questions:

- Who determines how our health data is collected, managed, stored and disposed of?
- What are the limits of this authority?
- How can we ensure this data is being used for public benefit purposes?
- How much access and control do and should individuals have over their health data?
- How can we ensure this ownership and control is respected and protected?

“Currently we have a system of health data extractivism where individuals hand over their data and then lose control over this most intimate information,” said Mathilde Forslund, Executive Director of Transform Health. “We need stronger regulation underpinned by ethical and human rights principles, that enshrine in law the rights and responsibilities of individuals in relation to their health data. My Data Our Health hopes to contribute to that outcome.”

“At the heart of the My Data Our Health campaign is the issue of trust in those collecting and using our health data, and ensuring it is used to keep us healthy – now and in the future.” said Allan Ragi, Executive Director of the Kenya Aids NGOs Consortium (KANCO), a campaign partner. “Effective health data governance is necessary to create trust between individuals and institutions and between institutions – for example, to facilitate the sharing of data between healthcare organisations.”

Follow NivalishePad initiative on social media pages (Facebook: <https://m.facebook.com/people/NivalishePad-Initiative/100080338822403/>, Twitter: <https://twitter.com/nivalishepadke>, Instagram: <https://www.instagram.com/nivalishepad/>;) to join the conversation!

How can you engage in the campaign?

1. Where’s My Data?





Take the Where's My Data? campaign action to contribute to the conversation on how much control we have over our health data and digital health information.

Go to your usual health centre and ask for your electronic health records or digital health information. Film a video sharing your experiences of what happens next.

Your experiences will be shared across the world to influence advocacy and public perception. Interested? Sign up!

[SIGN UP FOR WHERE'S MY DATA?](#)

2. Survey: How much do you know about your health data?

Take a 5 min anonymous survey on your health data. Anyone can take the survey, so share it around!

[TAKE A 5 MIN SURVEY](#)

Head to the [campaign webpage](#) to find out more ways you can engage!

How is NivalishePad Initiative engaging in this campaign?

Upcoming activities: -

- Capacity build media professionals on health data governance.
- Training social media influencers on health data governance.
- Stakeholder meeting with key legislators on health in Kenya.
- Community dialogues on health data governance.
- Content creation with youth advocates on health data governance.

